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ABSTRACT

The guide presents information for parents, advocates, residential counselors, or retarded persons on the use of drugs in behavior modification. Reasons for concern over the use of drugs are noted, and general principles regarding such factors as individual differences in metabolism and reaction, dosage level, and changes over time are discussed. Answers are provided to 31 questions frequently asked by parents regarding reactions of retarded persons, other types of management of behavior problems which should be tried before drugs, changes in reactions during adolescence, time of administration, side effects, effects of anticonvulsants on behavior and learning, and vitamins. A final section in the monograph considers the importance of fostering better communication between parents and professionals. (CL)

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M.R. RESEARCH

THE USE OF DRUGS TO MODIFY BEHAVIOR IN RETARDED PERSONS: A Practical Guide for Parents and Advocates

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THE USE OF DRUGS TO MODIFY BEHAVIOR IN RETARDED PERSONS:

A Practical Guide for Parents and Advocates

Roger D. Freeman, M.D.

Published by
NARC Research and Demonstration Institute,
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and
National Institute on Mental Retardation, of the
Canadian Association for the Mentally Retarded

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FOREWORD

The National Association for Retarded Citizens and the NARC Research and Demonstration Institute are pleased to publish this **Guide** on the Use of Drugs to Modify Behavior in Retarded Persons. It is designed to help guide the parent, advocate, residential counsellor or retarded person to know what questions to ask about medications, from those who prescribe and administer such drugs.

This **Guide** is written in clear, non-technical language describing the issues involved, the effects of various drugs and possible problems associated with these drugs. This publication is the result of years of work by Dr. Roger Freeman, who began his research in 1972; he received help and information from many parents and Associations for Retarded Citizens, as well as from professionals throughout North America.

This is a joint publication. The project has been funded and supported by both the National Association for Retarded Citizens (through the NARC Research Fund) and the Canadian Association for the Mentally Retarded (through its National Institute on Mental Retardation). The American and Canadian editions are identical in content but have separate covers, each linking the **Guide** to a monograph series. In the United States it is the **M.R. Research Monograph.** In Canada it is a monograph suppliment to CAMR's quarterly journal, **Deficience Mentale/Mental Retardation.**

Our thanks to Dr. Roger Freeman for a careful research effort and for his lucid interpretation of the results.

Dorothy I. MacConkey, Chairman
NARC Research Advisory Committee

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I would like to acknowledge the assistance of both national organizations; the many parents who took the time and trouble to write; the residential facilities who answered the questionnaire and hospitably welcomed me to their premises and openly shared ideas with me; Dr. Ronald Neman, Associate Director for Research of the NARC Research and Demonstration Institute; Dr. G. Allan Roeher, Executive Vice President of the Canadian Association for the Mentally Retarded; Dr. Franklin C. Smith, who stimulated the project in the first place; and several anonymous reviewers.

INTRODUCTION

Drugs are frequently used to modify behavior in retarded persons, but this poses many problems. Both the variety of medications and awareness of their possible ill effects have increased greatly in the past fifteen years. Parents and professionals share concern for responsible drug use – and both require a sound base of information.

In October of 1972, a member of the National Association for Retarded Citizens (NARC) Board of Directors proposed that a way be found to impart more information about drugs to parents, advocates and professionals. NARC approached me because of my previous review of the subject,* and I suggested that the Canadian Association for the Mentally Retarded (CAMR) participate as well. This was accepted, and the **Guide** has accordingly been sponsored by the NARC Research and Demonstration Institute and the National Insitute on Mental Retardation (the research body associated with CAMR).

There have been several factors which delayed the completion of this **Guide**. First, it was necessary to collect the ideas, experiences, concerns and questions of parents in both countries. This was accomplished through local organizations during the period from the end of 1973 through 1974.

It then became obvious, from visits to a few residential facilities, that professional practices and opinions differed widely. I felt that it would be useful to obtain questionnaire information from all public residential facilities in both countries. The development of a suitable questionnaire and obtaining the sanction of appropriate organizations took more time, but the survey was completed in early 1976 with the assistance of both sponsoring national organizations, the National Association of Superintendents of Public Residential Facilities in the U.S.A., and the various responsible ministries in the Canadian provinces.

Several words of caution are necessary:

- **This Guide is NOT to be used as a set of standards.** Knowledge and opinion are continually changing, and a certain amount of controversy and latitude is both realistic and essential, since there is much which is not known. Parents and practitioners should not construe this **Guide** to be a substitute for

* *Freeman, R. D. Psychopharmacology and the Retarded Child, In Menolascino, F. J. (ed.),* Psychiatric Approaches to Mental Retardation, *New York, Basic Books, 1970. Pp. 294-368.*

either manufacturer's information supplied with a drug or familiarity with recent literature.

- Chemical or generic names for drugs are used, but the commonest brand names (capitalized) are also given. In many cases there are other brands available with different names and no claim is made that the list given is complete.
- Mentally retarded persons differ much more from each other than many people realize. It is not very likely that a generalization (or an answer to a question in this **Guide**) could apply equally well to all.
- Finally, I am not including an evaluation of any claims to modify intellectual functioning itself by drugs, but rather the approaches to troublesome behavior.

Some physicians have doubted the usefulness of a **Guide** such as the present one: they seem to feel that there is no need for parents to know about details of drugs or their principles of action – this is the physician's area. And besides: some parents might make trouble for an already harassed staff – this they would naturally like to avoid. Others may suspect that the sponsoring organizations are anti-drug. However, parents **are** entitled to information, whether or not a few misuse it. It is hoped that the reader will realize that every effort has been made to be fair and yet realistic about current practices. The national organizations, I should make clear, have never attempted to influence my thinking.

It is hoped that any comments and criticisms will be forwarded to me or to the sponsoring organizations.

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Chapter 1. REASONS FOR CONCERN

> *"The nurses and attendants don't seem to know any way to manage the residents except by medication"* – a parent.

Prescribing medication is a specific medical act, perhaps one of the few things that only physicians – and no one else – can do for mentally retarded persons. It is often a quick procedure and this, combined with the physician's status and authority, causes some people to fear that drugs are being over-prescribed or used as a substitute for an adequate program, especially when funds are in short supply.

There is no doubt that a high proportion of retarded persons, especially those in residential facilities, are receiving medications and for long periods of time. The public is hearing more about unsafe drugs and long-range dangers, and is naturally suspicious. Most parents and professionals are very aware that some frustrated staff may press the physician for drugs to help control behavior which may not be that serious, may not be appropriate for drug management and which the physician may not have observed directly. Sometimes the drug side-effects seem worse than the problem for which they are given. The questions also arise: Should drugs said to be effective for severe psychiatric disorders be used for different kinds of disturbing behavior? And how well is their use being supervised?

The following kind of situation is not uncommon:

The retarded person is said by staff to show a particular type of difficult-to-manage behavior in the residential setting. The parents do not encounter this themselves in the home. Medication (or perhaps several kinds) is prescribed, but all the parents see is that their child is sleepy, and they wonder what is being accomplished, and why. They are reluctant to press the issue, but their feelings about the residence and its staff become increasingly negative. Meanwhile, the staff may be developing their own notions about the home: The parents seem uncooperative, or change the medication when the retarded person is home for a visit, or do not appreciate difficulties which occur in the residential setting.

This increasing difference in point of view between staff and parents can become a major problem, and may be difficult to resolve. Yet, surprisingly, the knowledge of how to interrupt this destructive spiral is often readily available. This is one of the purposes of this *Guide*.

It is all too easy to take polarized views: that medication is always bad, and should be avoided at all costs; or at the other extreme, that it should and must be tried for all troublesome behavior, purely at staff discretion and

without parental "interference". I believe that these extremes misrepresent reality, and that accepting either one of them leads to difficulties. Some retarded persons who could function better with medication may not receive it – others who need different types of assistance may be inappropriately medicated.

Controversy over drug use is an example of how readily "conspiracies" are assumed to exist. In this type of view, one can easily "explain" what is happening by claiming that "they" (parents, parent groups, physicians, drug companies) are deliberately scheming to create and maintain an unsatisfactory situation. Usually very little evidence is necessary to make a person who assumes this perspective feel his view is correct: you can easily find, for example, that:

- Some parents are unreasonable, oversensitive, suspicious, interfering or anti-drug on principle;
- A parents' organization may take an extreme position;
- Drug companies *do* profit from increased drug sales and use;
- Government does not take sufficient interest in better programs;
- Some physicians are arrogant, will not listen to parents' observations or legitimate worries and want to do as they please without criticism;
- Evidence for safety and effectiveness of drugs, and the quality of studies required by government, are sometimes inadequate – occasionally shockingly so – or at least the media appear to give this impression.

These examples are given to indicate that there is always information available to cause concern and even to appear to justify a conspiracy theory. While seeking improvements and dealing with definite abuses, we must beware of our own tendencies to exaggerate, build a false case on slender evidence, or assume a conspiracy where none exists.

I believe the situation is usually much more complicated than it seems, and that very unfortunate situations can develop and persist *without* any conspiracy – even where all parties are well-intentioned. And that is my own assumption in writing this *Guide* in an attempt to remedy, in some small measure, the present state of affairs.

Chapter 2. GENERAL PRINCIPLES

There are a few ideas that should be kept in mind while reading this *Guide*:

What the Label "Mental Retardation" Does – and Does Not – Mean

Mentally retarded persons do not actually share many characteristics besides their label. There is a great danger in forgetting to ask the question: "how much information does this particular label carry with it *in this particular instance?*" Unless one realizes that all labels have their limitations, one can either expect too much of them or become convinced they are useless and throw them out entirely.

Within the group with which we are concerned, there are great individual differences in personality and behavior, skills, associated handicaps, abnormality of the nervous system, cause of the retardation, family circumstances, tested intelligence level and so on. Therefore, one would not expect many generalizations to apply when the group is so mixed. One which does apply is *lower general intellectual functioning* (and I am leaving out of consideration here how that assessment is made and the problems in testing).

So what are the implications of the label? There will be less ability to comprehend and integrate complicated situations and ideas – and to cope effectively when situations become stressful. Also, there is an increased likelihood (which increases with a decrease in the level of intellectual functioning) of abnormalities in the nervous system, of other handicaps, of major language problems and of psychiatric disorders.

The majority of *mildly* retarded persons have no obvious medical abnormalities; but most who are moderately, severely or profoundly retarded do. This is one factor in psychiatric disorder (see below). In summary, then, the more retarded the person, the greater the likelihood of abnormality in body (and brain) function.

Psychiatric Disorder and Behavior Disorder

Children with evidence of malfunction of the brain are known, through conclusive studies, to have a much higher rate of psychiatric disorder.* This

* *In this Guide, the use of psychiatric disorder does not mean "insanity," nor that psychiatrists are the only ones who should deal with the problem. There has been enough confusion already over the word "mental" in mental illness and mental retardation. For the purposes of this guide, 'psychiatric disorder' means abnormalities of emotion and/or behavior sufficient to be significantly handicapping to an individual or those around him or her.*

is one factor, but not the only one, as the higher rate is present even in the group with no sign of brain dysfunction.

In looking at *why* retarded persons have a higher rate of psychiatric disorder, several factors are of importance, but the *causes* in each particular person may differ, and this list should not be taken as complete (or in order of importance):

- organic brain disease or dysfunction
- family and social problems
- language limitations
- temperament; persisting early behavioral trends such as high intensity of response, irregular functions (e.g., feeding and sleeping), poor adaptation to new situations
- social rejection and educational failure
- prolonged abnormalities in biological and environmental functioning.

Behavior does not have only one cause, but typically many, some of which are unknown. It is therefore reasonable to be suspicious of anyone who claims to know *the* cause of "disturbed behavior", whatever that is. This caution also extends to professionals who explain behavior by saying "that's because he's retarded".

Even though we may never know all the causes, this is no reason to despair: interrupting a chain of causative factors will often improve behavior anyway (as an antibiotic may cure an infection even though there is much we still don't know about that infection and the drug).

People often disagree on what the "disturbing behavior" is, its causes and its management. There is clearly a large *social component* in what is called disturbed or disturbing behavior. (Hitting someone may be a reaction to what the other person has done, a substitute for getting back at someone else, an apparently purposeless act related to poor impulse control or actually a response to hallucinations or delusions.) The *interpretation* of what happened, or even whether it happened, is complicated. It depends upon the *type* of behavior, how often it occurs, how openly, the level of supervision and observation, the individual's personality and comprehension, the organization of home, community or residential facility, and sometimes simply upon personality clashes and likes and dislikes.

Drugs are given both for "mental illness," that is, severe psychiatric disorder such as schizophrenia or other psychoses (which are more difficult to diagnose the more retarded and multihandicapped the person) and for particular types of behavior such as aggression towards others (or self), overactivity or sleeping problems.

Some types of behavior are more likely to occur in one setting than another. This often leads to misunderstandings between parents and others – and calls for willingness of each observer to consider this possibility. (The best-known example is restlessness at home and at school, which depends upon the different kinds of activities expected of the child in each setting.)

Sometimes unusual habits or behavior patterns have developed over the years in a retarded person, and no one has any useful notions as to why or how. At other times, behaviors may come and go for no apparent reason. Sometimes parents have found their own ways to deal with (or live with) these patterns – ways which professionals do not understand, or which are even thought by them to be the cause of the behavior. This, of course, can be another source of misunderstanding.

Behavior which occurs only rarely – even though very dramatic – may not be influenced very helpfully by drugs without making the person unacceptably sedated.

An adequate understanding (which can lead to helpful solutions) of a behavior pattern is more likely to be accomplished if those in contact with the retarded person share information and observation from their different perspectives in an open-minded way.

Individual Differences in Metabolism and Reaction

Although there are some general guides, drugs are not necessarily broken down (metabolized) at the same rate or in the same ways in all individuals (or in children and adults), so one person may have quite a different (or even opposite) reaction from another. And these differences may be even more extreme or unpredictable when there are abnormalities in brain function or other body systems. Caution is therefore necessary; each person and each drug is to some extent unpredictable, even though the drug may be well researched and accepted.

The effect of a drug may also depend upon many other factors, some of which will be covered in the next chapter.

Effect of Dosage Level

Drug effects may occasionally be in opposite directions at different dosage levels. For example, a certain level may lower the frequency of a type of behavior while a higher dose may actually increase it.

Changes Over Time

The nature of the effect may change over time. This is also true of adverse (unwanted) effects – some may lessen or disappear in a few days or weeks – others may only appear after a delay. Sometimes side effects may

appear *before* the desired response, and disappear later.

Types of Unwanted (Adverse) Reactions

There is a difference in adverse effects between those which are dose-related and often *predictable* (like dry mouth or constipation, for example) and those which are unrelated to dose and may be allergic and sudden in onset. In the latter case, something has happened to the individual's body chemistry which may have permanently affected his response to any amount of that drug – such as occurs in a penicillin reaction.

New Drugs

Drugs which are new on the market should, most clinicians agree, be used with greater care and a higher level of observation than better-known drugs. Many prefer to avoid them until there is more knowledge available – unless there is no alternative, such as when other older drugs and other procedures have failed. Often the newer drugs prove to have no advantages over the older ones. Research may produce a drug which is useful specifically because it has fewer side-effects than an older drug.

Fixed Drug Combinations

There is general agreement that two or more drugs (in fixed combination with each other) should not be used. It is better to use drugs separately, because the dosage of each can be individualized.

Number of Different Drugs Given Simultaneously

Also agreed is that the fewer the drugs, the better. When several are given, the way other drugs are used or broken down by the body may be altered, and it becomes more difficult to know which drug is creating which desired or undesired effect.

However, many retarded persons also have epileptic seizures and therefore receive one or more anticonvulsant drugs which act on the central nervous system and may complicate the administration of psychoactive drugs.

The effects of several drugs on the central nervous system may be more than *additive* – that is, more than the effect you would expect from giving them separately and then adding, in your mind, what the result would be like. And this may include combinations with alcohol, over-the-counter cold remedies, antihistamines for colds or allergies, etc.

Drug Potency

The potency of a drug and the likelihood of side-effects are not always related to the number of milligrams of the dose – do not expect the number to tell you much by itself.

Chapter 3. QUESTIONS FREQUENTLY ASKED BY PARENTS

> *"Whenever I ask questions about drugs, I am told that I don't understand how they work. But I sure can see what they do."*
> — a parent

1. How do drugs change behavior?

Although many details are still unknown, drugs probably act by modifying the transmission of electrical impulses. (There are several kinds of chemical transmitters of messages from one nerve cell to another, depending upon the part of the nervous system involved, and whether the "message" is sent or stopped, amplified or reduced.)

A drug will not necessarily produce "normal" behavior in someone who has never shown it, but it may make new patterns of behavior possible in combination with environmental changes, and may reduce the frequency of certain behaviors. Mood may also be altered. Drug changes will therefore be most beneficial when the person's relationships, living and learning situations are modified so as to facilitate changes. For example, an agitated, restless person who has been pacing about and unable to concentrate *may* be better able to develop social relationships and learn other patterns if the agitation is reduced by means of drugs – but the medication does not provide the necessary environment. Sometimes the social changes are so beneficial that the drug can be withdrawn and the new behavior patterns will be maintained.

2. Are retarded persons different in their reactions to psychiatric drugs? Must treatment for them be different?

Generally, individuals who are retarded are similar to those who are not. However, there are four special limitations to this statement:

- If the retarded person has brain malfunction or some other biological peculiarity, drug effects and also appropriate doses may be different. It is best to start out cautiously.
- Many retarded people will have limitations in expressing their subjective feelings or describing unpleasant symptoms, making it harder to tell what is going on. This calls for more careful observation than would be necessary for a person who can be counted on to report changes spontaneously. Along with this reduction in expressive ability, explanations may either not be given or may be impossible: sometimes drug side-effects have to be put up with temporarily, and reassurance of the patient helps – some retarded persons may become agitated because of the lack of understanding or explanation of this kind. The parent may be able to give an explanation when the professional would find it difficult or impossible to do so.

- Many people who are retarded will be taking other medications, such as for epilepsy, which makes awareness of drug interactions essential.
- At the more severe levels of retardation, psychiatric diagnosis becomes more difficult and the usual "target symptoms" that are used as indications for drug use may be partly obscured.

3. What other types of management of a behavior problem should be tried before drugs?

It depends. In some cases (always assuming an assessment has been done) drugs are the most useful treatment and should be the *first* method (treatment of choice). This would be the case with psychotic reactions such as schizophrenia, particularly with an acute or sudden onset. (Of course, that does not mean that drugs are the *only* form of treatment.)

In other instances, something else may well be called for – behavior modification (systematically examining and changing what happens before and after the problem behavior), individual counselling, changes in living, learning, and work situations (e.g., less restrictive environments), parent counselling, group therapy – in short, anything which might beneficially affect any person with a problem due to similar causes.

But frankly, these other methods may be unavailable or take much more time than drugs – so we are back to that same old problem of potential overuse or substitute-use of drugs.

Thus, the question can only be answered rather lamely by saying that it all depends upon a good evaluation and an appraisal of where in the causal chain – given available resources – one can intervene. There are problems at each point in this kind of process – but it will help to avoid an "all or nothing" philosophy.

Studies are now being done which show that for some types of problems, behavior modification can be as effective, or more effective, than drugs, or that both combined may be better than either separately. Further evaluation of the place of drugs combined with behavior modification is needed.

4. What kinds of behavior warrant drug treatment?

There are several. Psychosis, with symptoms such as extreme agitation, disordered thinking or mood, loss of contact with reality, and hallucinations or delusions, is one. Marked overactivity, difficulty sleeping, frequent aggression towards self or others, and depression are other possible indications.

5. What should I look for after a new drug is used for my child, and how soon?

The desired results will depend upon the reason for which the drug was given – but usually it will be a reduction or elimination of undesirable behavior. The person prescribing the medication should be able to tell you how long the change should take to appear, whether increase in dosage may be necessary (it often is), and what (if anything) to do if worrisome or dangerous side-effects show up.

Remember that many side-effects, such as sleepiness and dryness of the mouth, are temporary.

6. Are drugs misused?

Sometimes yes, unfortunately. Procedures to safeguard experimentation with mentally retarded people have been put into effect in many areas recently; often these involve research screening committees in which parents and non-professional citizens are involved. If, as a parent, you are worried about this, you can usually find out about legislative requirements through your local association for retarded citizens.

Other forms of abuse include:

- Using drugs inappropriately as substitutes for programs;
- Using drugs in spite of lack of assessment and documentation of individual need, or to prevent an infrequent or unlikely outburst;
- Using a larger number of drugs or higher dosages than necessary;
- Adding a drug to those already being given as a result of a temporary crisis, without careful investigation.

Some safeguards here are:

- promoting parental awareness of drug use and abuse;
- ensuring good communication with the physician;
- monitoring your state or provincial program and its funding;
- assuring that programs fulfil the standards which have been established by accrediting organizations;
- promoting awareness by parents of public-participation committees set up to advise or monitor residential facilities;
- ensuring that psychiatric and pharmacologic consultants are available; and
- working to maintain and increase the effectiveness of associations for retarded citizens.

7. What are the different kinds or classes of drugs used?

First, it is essential to realize that *most drugs* (of any kind) can have many effects, both beneficial and otherwise. Therefore, if a psychoactive drug* turns out to be useful in some form of heart disease, this should not surprise you. Many times parents are puzzled: they have heard that a drug is of a certain kind – for example, an antidepressant or stimulant – and they cannot understand why their child (who is not apparently depressed or seems overstimulated) is being given this type of drug.

Second, classification is somewhat arbitrary because of the multiple actions and different points of view. You could divide them up on a chemical basis – but since very different chemicals may have the same effects, or two closely related ones very different results, that is not too useful for our purposes.

Below is a very brief classification of drugs which modify behavior, with some common chemical and brand names and side-effects. (This is by no means complete in these respects.)

Brief Classification of Psychoactive Drugs

A. *Major Tranquilizers* (also called "antipsychotic" or "neuroleptic" drugs) reduce anxiety, agitation, hallucinations and delusions. They are most useful for psychosis, but also for some other problems.
Examples are: chlorpromazine (Thorazine, Largactil); thioridazine (Mellaril); trifluoperazine (Stelazine); halperidol (Haldol); fluphenazine (Prolixin, Moditen); mesoridazine (Serentil).
Side-effects include: sleepiness, depression, low blood pressure, eye and liver changes, skin pigmentation and sensitivity to sunlight, increase or decrease in seizures, sometimes seizures in someone who never had any, constipation, difficulty in starting to urinate, weight gain, and abnormal movements.

B. *Minor Tranquilizers* (or "antianxiety agents") have limited use for retarded person, especially children. Results are unpredictable.
Examples are: diazepam (Valium); chlordiazepoxide (Librium); meprobamate (Equanil); clorazepate (Tranxene); oxazepam (Serax); hydroxyzine (Atarax, Vistaril).
Side-effects include: increased agitation, nightmares and sleepiness.

C. *Antidepressants* are used to elevate mood, reduce bedwetting, and some authorities consider them useful for overactivity and excitable behavior.
Examples are: imipramine (Tofranil); amitriptyline (Elavil); doxepin (Sinequan); desipramine (Pertofrane, Norpramin).

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* *Sometimes referred to as "psychiatric", "psychotropic", "psychopharmacologic", or "psychotherapeutic" drugs.*

Side-effects include: changes in heart function, dry mouth, urinary retention, skin rash, seizures and increased agitation.

D. *Stimulants* increase the activity of part of the nervous system.
Examples are: methylphenidate (Ritalin); dextroamphetamine (Dexedrine); pemoline (Cylert).
Side-effects include: insomnia, loss of appetite, overexcitability and tearfulness.

E. *Sedatives* may be used to slow an individual down or to induce sleep. They may impair coordination and intellectual functions.
Examples are: barbiturates, chloral hydrate, paraldehyde; flurazepam (Dalmane) and many others.
Side-effects include: stomach upset, irritability, hangover and addiction if used for prolonged periods at high doses.

F. *Anticonvulsants* raise the seizure threshold. They may have other effects such as tranquilization.
Examples are: phenobarbital, phenytoin (Dilantin); primidone (Mysoline); ethosuximide (Zarontin); carbamazepine (Tegretol).
Side-effects include: swollen gums, sleepiness, poor coordination, slurred speech, and psychosis or increased psychiatric disorder.

G. *Antiparkinson* drugs are used to counteract nervous system side-effects of other psychoactive drugs, especially the major tranquilizers. The latter may produce abnormal muscle spasms or movements, or symptoms like those in Parkinson's Disease (tremor, rigidity, drooling, etc.).
Examples are: benztropine (Cogentin), trihexyphenidyl (Artane).
Side-effects include: dry mouth, constipation, depression, weakness, nausea, urinary retention.

8. What changes in reactions to drugs may occur at adolescence?

Since some maturation of both the central nervous system and body systems which metabolize drugs take place up to puberty, changes in drug reactions and effectiveness may occur. Also, there are large changes in sex hormones and social interests, which may influence behavior.

This may require reconsideration of the total program for a retarded person, not just drugs.

Stimulant drugs, sometimes used for retarded persons who are overactive or distractible, may become less effective after adolescence, but this must be individually determined.

Changes in seizure patterns may also occur at this time and require readjustment of medication.

9. Are all brands of the same drug equivalent?

This is a complicated and even political issue. If the chemical processes in manufacturing the drugs are identical, then the drugs will be the same, despite different names. Sophisticated and expensive tests may be necessary to determine this, however.

For example, there may be impurities, different rates of deterioration or differences in how readily the tablet dissolves or is absorbed. This will influence the blood level achieved.

Governments are now requiring more information of this sort before approving drugs. But the only way to be absolutely certain is to test what is called "bioavailability", or the amount of active substance delivered to the appropriate part of the body. This is not necessarily the same as chemical or physical tests in a laboratory.

This can be a political question because of advertising campaigns and claims, and because of legislation in some parts of North America which permits (or requires) a pharmacist to provide the lowest-cost substitute, rather than the brand the physician has prescribed.

These issues are not completely settled, and the scene will probably change in the next few years. You may, therefore, encounter local differences and strongly-held preferences of physicians, clinics and residential settings.

10. How long should a drug be continued?

As long as the indications of need are still present. This can be determined by the total situation and by periodic discontinuance.

Some drugs can be continued indefinitely with minimal risk, while others cannot. Only close monitoring will ensure that risks are minimized. Anticonvulsants, however, may need to be given for years, or until several years have passed with complete seizure control. No rules can be given here — each situation is different.

Policies are being developed in some states and provinces to require documentation of changes in behavior during drug therapy. Efforts are also being made to decrease the number of different drugs and their dosage to the lowest possible level.

11. How many different kinds of drugs should be given?

The obvious answer is: the smallest number to do the job(s). If one can do it, so much the better. But often two are needed, one as the major drug, and one to control side-effects, or as an anticonvulsant in someone with seizures. Epilepsy may require two or more drugs, so that it is not rare for

someone to be taking 4 drugs which affect the nervous system. It is not possible to specify an upper limit to the number, however.

12. How many times a day should a drug be given?

This depends upon the metabolism and how the drug is given. Obviously, a drug given by injection will act faster. Time-release forms are available for some drugs. In some cases, a "depot" form may be used for injection once every few weeks. This is a special preparation which is absorbed very slowly and which is most useful for disturbed individuals who are outside residential facilities, uncooperative and forgetful about taking medication, and for whom the drug is definitely necessary.

Recently, there has been a lot of publicity about once-daily administration of drugs instead of the traditional 3-4 times a day. No general rule can apply to all these drugs, however. It all depends upon how long the drug takes to reach an adequate blood level, and how long it is maintained before falling below that level. There are individual differences in these rates as well. Some drugs build up in the body for several days and can then be given once a day (e.g., at bedtime). Others cannot.

There is still some disagreement about these issues and how to put available information into practice. If your physician changes administration of the drug from several times to once daily and there is a change for the worse, this must be discussed.

13. Why are the drug doses given children sometimes so high compared with adults?

This again concerns differences in types of drug and in the ways the body uses drugs. Body weight is only one factor, and others may be more important. Sometimes a child may need a dose just as high as an adult, though generally one starts with a lower one.

14. Should drugs be given before, during, or after meals?

Sometimes this matters; sometimes it does not. When it does (which your physician should be able to tell you), it may be because the drug is irritating to the empty stomach, or because its best absorption depends upon whether food is present or absent.

15. Are drug samples safe to use?

Sometimes a physician will dispense a drug sample rather than giving a prescription. This is generally safe, provided the medication has not passed its expiration date. (Some drugs are very stable for years; others are not.)

The physician may do this to save you money for a trial of a drug new

to your child. Then if it seems effective, a prescription for a larger amount may be given. It does not mean he is experimenting with an unsafe drug!

16. Is there anything wrong with the parent adjusting dosage of a drug?

Yes, sometimes. Physicians differ in how much discretion they will allow a parent. Sometimes a drug is dangerous if given beyond a certain level or frequency. At other times a parent may give a behavior-modifying drug at the wrong time, either in anticipation of an upsetting or exciting situation or after the situation has started to improve. Some drugs cannot be used in this way – they take too long to act. An occasional parent may misuse a drug to punish "bad" behavior in such a way that the retarded person feels this intention and reacts against it (as, for example, a person afraid of falling asleep "fights" a sedative and gets more, rather than less, excited).

Reduction of dosage may cause an aggravation of behavior problems; it should be attempted only under supervision of the physician.

Physicians who allow parents to use their own judgment usually know the family well, trust the parents and describe the limits of the flexibility to be allowed. They may, for instance, prescribe a basic dosage and indicate that an extra dose may be given as needed, on top of that. Common or dangerous side-effects should, of course, be described to the parents.

17. When drugs are discontinued, should this be gradual or sudden?

This depends upon the type of drug and dosage level. With high doses of some major tranquilizers, sudden reduction may uncover severe physical reactions involving abnormal movements. Generally, it is better to reduce dosage slowly unless severe side-effects make discontinuance an emergency matter. With stimulants, tapering off is not necessary.

18. What about "hyperactivity" or "hyperkinesis" in retarded children?

This field is very confused in North America. There are, indeed, a few children of normal intelligence who are consistently overactive – that is, they show increased activity levels in all or most situations. But there has been much confusing publicity about this. *First*, retarded persons may appear to be more "active" and restless than those of normal intelligence. *Second*, activity *level* has often been confused with other things, such as distractibility, the way behavior is organized and problems with attention. In any event, hyperactivity is not a "disease" and does not have a "cure". You should beware of those who have simple answers to this so-called problem. almost everything has been attributed to it (including crime, delinquency, and behavior disorder), and there are all sorts of "treatments" which are unproven.

19. Why are "stimulants" sometimes given to retarded children who are already overactive?

These drugs, though not well evaluated in retarded persons, seem to stimulate *inhibition* – that is, the balance between doing and not doing, or responding and not responding. Retarded persons are much more likely than those of average intelligence to show overactive or poorly organized behavior.

Stimulants are frequently used in children whose ability to attend is reduced, in hopes that this will improve their ability to learn. The follow-up studies now available are not very encouraging, however, in that such treated "hyperactive" children seem to do no better in the long run, although for many there is an improvement over a short period of time. Fortunately, most of these drugs act quickly – if at all – and one can usually tell in a few days whether or not they will be useful.

20. What are some of the problems in using stimulant drugs? Could they lead to drug use later on?

Many people have heard about smaller weight and height in children given this class of drug for long periods. It now seems this is not a problem, as growth catch-up occurs later. Many children, however, do become thinner and this worries their parents. This type of drug is habit-forming and may be abused by adults. But the effects on those children for whom it is prescribed are different, and several follow-up studies show no increase in drug abuse in adolescence or later.

The drugs are said to work in about two-thirds of children who are not retarded. This proportion is probably lower for retarded children.

They may make some children slow down too much, appear in a daze, or be tearful. Sometimes this stops with a reduction in dosage; in other cases, the child becomes more restless, and the drug must be discontinued.

21. What are the different types of side-effects?

The simplest undesirable effects are predictable exaggerations of chemical effects based upon the dose and class of drug. Common examples are sleepiness, dry mouth, blurred vision and urinary retention.

Other (usually more severe) reactions are unpredictable and may be unrelated to the dose or how long the drug has been taken. Some are true allergic reactions and there may be inherited peculiarities in certain individuals which make such reactions more likely.

This is a complicated subject which is gradually becoming better under-

stood. Only a few aspects are considered in the following sections.

22. Can one drug interfere with the effects of another?

Yes. Sometimes that's exactly what you want: one drug to counteract the undesirable side-effects of another. But at other times one drug may affect the way in which the body handles a different drug in complicated ways. Much more is known about this now than in the past, but the number of possible combinations is endless, especially if you consider that interactions can occur not only between prescribed drugs, but even with certain foods and over-the-counter medicines.

23. What are the most important or dangerous side-effects to watch for?

- Persistent or severe sore throat; easy bruising; fever;
- Swelling (including hives) of skin and in throat;
- Abnormal movements of face, tongue, eyes, hands, etc.; increased restlessness
- Skin rash; asthma;
- Inability to pass urine or to have bowel movements;
- Jaundice (yellowish colour of skin and whites of eyes);
- Increase in seizures or seizures when there were none previously.

These need to be evaluated in relation to previous symptoms, not just by themselves – they are therefore most significant when occurring for the first time.

24. What kinds of examinations or tests should be done?

- *Physical examinations* should be performed on a regular basis (probably once a year at least), and more often if there are special problems or symptoms or if there is an unusual number or dose level of certain drugs. Some drugs have effects on the heart or liver, for example, and any problem with those organs should be identified before medication is begun. Most facilities have a policy, but there is no absolute agreement on this, and some parents expect more from the procedure than it is likely to yield. If parents and staff have good communication, then suspicions that something is wrong will be more likely to be investigated promptly.
- *Blood tests.* Many residential programs have a policy to do a battery of blood tests one or more times a year on residents receiving certain drugs. This practice is highly variable and often is done for medico-legal reasons. Unfortunately, these tests are not very useful for the most severe reactions, which tend either to occur suddenly or not show up on tests at all.

Generally, the blood tests are used to measure the effects on blood production (such as anemia) or on liver function. Newer tests for some anticonvulsant and psychoactive drug levels are very useful to determine whether the right blood level has been reached (regardless of the dose taken by mouth). (This field is constantly changing, as are regulations and policies.) It is certain that tests of drug blood levels will become increasingly important in the future.

(It should be pointed out that most physicians do *not* do any tests on their patients who live outside residential facilities who are on ordinary doses of one or two psychoactive drugs.)

- *Urine tests.* The frequency, kind and usefulness of these are also controversial.
- *Eye examinations.* Some drugs, such as thioridazine (Mellaril), can produce changes in vision if taken at unusually high doses for long periods. Other dugs cause minor and non-significant changes in the eyes. Therefore eye examinations, including slit-lamp, may be advisable. However, this may be difficult to do because it requires cooperation – in some cases sedation or general anesthesia might be necessary. Policies differ. But the physician should know the few drugs which can cause problems (the information is readily available) and act accordingly. If you think there has been a change in vision (such as might be evident from difficulty in getting around or picking up small objects, or stumbling into things) you should discuss this with the physician in charge.

25. What can be done if a retarded person seems sleepy or dazed on drugs?

First, one should determine when the change started and variations within the day. This may give some clues. There may be reasons other than the drug.

Second, if it is agreed that this seems drug-related and is interfering with activities, discuss it with the staff in charge. It may be true in one setting (home, for example) but not in another; or it may be temporary and wear off soon. In this case, it helps to have a time limit in mind to assess the situation.

Third, trying different drugs, combinations or dosages may eliminate the problem.

Fourth, occasionally a stimulant drug can counteract the sleepiness, but this should be used with caution because of the general rule to try to keep the total number of drugs to a minimum.

26. Can chronic constipation cause behavior problems? Is it due to drugs? What can be done about it?

Severe constipation can certainly be uncomfortable, can cause cramps,

or pain from piles or anal fissures. It is not dangerous in the "toxic" sense, however.

Some retarded persons seem to have poorer intestinal function anyway, but in others the constipation may be due to a combination of factors such as inadequate toilet training, poor diet, lack of exercise, low fluid intake and drug side-effects.

Unfortunately, many of the psychoactive drugs may produce or increase constipation (sometimes to a severe degree). If this occurs, consideration should be given to changes in diet, fluid intake and exercise. Prune juice or increased roughage may help. Stool softeners may be necessary, but laxatives, cathartics and suppositories should be avoided as much as possible because they become "habit-forming" and the bowel may become even more sluggish when they are discontinued.

27. My child's IQ score dropped after being on a drug for a few years. Why? Has his brain been permanently damaged?

Although some of the drugs may impair learning, this is usually a temporary effect. They will not "damage" the learning processes. But, if prescribed at high levels, performance on a psychological test may be temporarily depressed and the IQ figure will drop. If used for years in such a way that awareness of the environment is reduced or a necessary program is not provided, it is possible that new learning may not be acquired. (See also Question 30 below.)

But the IQ score may drop for many other reasons that have little or nothing to do with drugs. IQ (in some tests) is a ratio between "mental age" (as compared with the general population) and chronological age. In other words, if *for any reason* a retarded person does not keep learning the types of things inquired about on IQ tests, the IQ *must* drop. Another point to keep in mind is that when a person becomes old enough to be given a different psychological test, the new IQ may not be exactly equivalent to the previous one, because the tests may not be equivalent.

This can be a source of misunderstanding. Do not assume that all changes are due to taking medication.

28. I'm scared of the effects of a particular drug on my child. I took it once and it made me sick.

I received several similar comments or questions. Of course the same bad reaction *could* occur, but individual differences in drug response are large, even within the same family. One should try to beware of the natural tendency to think that "my child will react as I did" or "my child is feeling the same as I would under the circumstances". Generally this assumption is not true, though occasionally it may be.

29. What are the signs that a change in medication might be necessary?

Changes in behavior or side-effects may be indications that a review is called for. If periodic discontinuance (a "drug holiday") is tried, then it may become obvious that there is *no* change without the drug. A decision may then be made to stop it or try something else, depending on the total picture of functioning.

30. What are the effects of anticonvulsants on behavior and learning?

There is much which is not yet known about the detailed effects of each drug. It is often a question of balancing control of seizures against the sleepiness or loss of ability to attend and learn which may be caused by high doses of anticonvulsants. Sometimes better seizure control improves behavior, learning and performance; occasionally it impairs behavior. (This is one reason why control of seizures is so complicated.)

At times, in order to have the retarded person more alert, or to have fewer side-effects, it is wiser to abandon the desire for complete seizure control. But usually anticonvulsants can be taken without serious problems. If there seems to be a change for the worse, the observations should be discussed with the physician in charge.

Blood levels can now be determined for some anticonvulsants, which helps to make sure that the person is receiving an adequate dose.

It needs to be realized that phenobarbital, often given alone or in combination with other drugs as an anticonvulsant, loses its sleep-inducing effect quickly. In fact, phenobarbital is not a good "sleeping pill" for prolonged use, for this reason. In some cases it may make a child more active or irritable.

Like almost all other drugs, the effects of anticonvulsants depend partly on circumstances; behavior at home may differ from school or residence. Observations should be shared by parents and professionals.

31. Are vitamins of any use?

There are many opinions on the usefulness of vitamins in large doses ("megavitamins") in mental retardation, as well as in learning and behavior disorders. The claims for dramatic changes have generally not been substantiated. There are, of course, some children and adults who may have a true vitamin deficiency with a variety of physical and other manifestations. Those who are convinced that vitamin deficiencies are neglected as causes of behavior disorders will not be dissuaded by questioning the present evidence.

Vitamin supplementation is important for those persons who have a peculiar or inadequate diet and for some who take anticonvulsant medication. Extra vitamins generally will not hurt, but *some* are toxic (the fat-soluble

vitamins A,D, K) because the excess which is unnecessary cannot readily be excreted through the kidneys like the water-soluble vitamins B and C.

Opinions vary widely and there are many books available to parents which express theories which are not as yet well founded.

FURTHER COMMENTS

Limitations of information on drugs

Most drugs have "package inserts" with the original package which give details of the dosage, side-effects and other information. This is also provided in many drug advertisements in medical journals. Some public-interest groups have publicized these details, but their limitations need to be better appreciated.

Some of the adverse effects which are listed are not only uncommon but also very rare. Sometimes these have not been fully established as being due to the drug though they were reported anyway. For example, the symptoms of an undetermined illness occurring at the same time as a new drug is taken may be blamed on the drug (e.g., dizziness, upset stomach and abdominal pain).

It is impossible in some cases to distinguish a drug reaction from some other cause, although observation and the passage of time may assist in the decision. Sometimes discontinuation or lowering of dosage is advisable even though the drug has not yet been proven to be the cause.

Of course, new possible or confirmed reactions are being reported all the time, and previously suspected ones are being removed from the list. Some are realized to be more or less serious than previously thought. Therefore, no list can be complete or final.

If you were to read the detailed information on any drug, no matter how well established (even aspirin), you would probably be afraid to take it. This is not to minimize hazards, but to explain how difficult it is to present such information in a balanced manner.

Chapter 4. FOSTERING BETTER COMMUNICATION

> *"The attitude and approach of the supervising physician is so important in drug therapy. The ability to be open and supply information freely – perhaps before parents ask – and certainly to repeat reassurances and encouragement was appreciated by us."*
>
> – a parent

> *"Deep down we parents of institutionalized children are afraid the institution's response will be 'if you don't like what we're doing, take your kid home'. And most of us would never have placed our child in the first place if we could have managed him at home."*
>
> – a parent

We all know how important good communication is. But how can it be established, improved or re-established (if it has broken down)? During the survey of parents' concerns, this was probably the one theme which was most commonly expressed. They complained that: physicians lack time, they don't take parents seriously and are authoritarian; the parents don't know the relevant question to ask or how to put them into words.

Surely, it is much easier to deal with facts than to develop communication skills – both for professionals and for parents. But drug use is only partly based upon facts – there are many areas of disagreement about patterns of practice, and individual differences in attitude and skill.

What are Some of the Obstacles to Communication?

- An assumption that the area of understanding and shared meaning is larger than it really is. Often the words used *don't* mean the same thing to a parent and a physician – but this may not be discovered and clarified between them.
- Lack of time for listening and clarifying.
- Inability to consider the point of view of others; prejudices.
- Parents may not know their rights or exercise them effectively.
- The behavior of the retarded person may actually be different in different settings, leading to a strong basis for disagreement between parent and professional.

Some Useful Ideas

Here are some suggestions which may help minimize problems in communication, although they cannot be expected to eliminate them.

(1) Start with the positive assumption that something constructive can be done, that the other person may be more reasonable than you think, or that the problem may be partly due to mutual difficulties in communication.

(2) Think through, and write down, your observations and concerns so that you will not be as likely to become flustered or confused in a personal meeting with a professional.

(3) Document your efforts to solve a problem: Who you talked with by phone or in person, on what date, at what time; keep copies of letters you send and a summary of other contacts; if you are in the midst of what appears to be a difficult and prolonged controversy, it may be helpful to summarize your understanding of contacts in a letter and invite comments from the person involved.

(4) Initially, work through channels. Do not jump over the different levels to the top. If you do, the senior person will be put in the position of having to defend someone who has not been given a chance, and you will seem to be a trouble-maker regardless of the merits of your case.

(5) When you get a reasonable hearing or consideration, write a letter of thanks with a copy to that person's superior. This makes good psychological sense for several reasons. Professionals are often under attack, and everyone likes to feel appreciated. Also, it may make that person more likely to deal constructively with parents in the future. And if you ever do encounter another conflict and are accused of being overly critical, you can prove that your approaches to professionals have not been only negative.

(6) Use your local parents' association and parents' advisory council of a residential facility (if there is one). See that common problems are identified and discussed and that attempts to deal with them are shared and evaluated; sometimes these should also be passed on to state-provincial or national levels, to government departments, and to professional associations.

(7) Support the establishment of liaison arrangements between parents and residential facilities, government programs and profession[illegible]societies.

(8) Remember that it is usually possible and helpful to discuss concerns and frustrations with others whose judgment you trust (parents, family physician or pediatrician, etc.) before taking action. In the midst of emotional involvement, it is hard to be objective.

(9) Find out your rights. And if you are convinced that you are not being properly considered, do not worry too much about the feelings of professionals.

(10) Be cautious about stories you hear which have been passed on through

several persons – they will usually be distorted. Also, read items in the news media with care – they are not always accurate. Use similar discretion in complaining to others, particularly about individual professionals – you may be embarrassed to have to correct the exaggerations fed back to you later!

(11) Last, but not least, listen to the feelings and ideas of the retarded person whenever this is possible.

AFTERWORD

Abuse of drugs will likely lead to more demands for guidelines and restrictions, and a tendency to reject medication even when appropriate. If the only thing which governments do not restrict, in a time of financial crisis, is the physician's right to prescribe drugs (while programs and staffing suffer), then drugs will inevitably be misused.

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